DOCUMENT RESUME

ED 321 216 CG 022 665

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TITLE Preserving Elder Autonomy: Moral and Ethical Considerations.
PUB DATE Mar 90
NOTE 12p.; Paper presented at the Annual Convention of the American Association for Counseling and Development (Cincinnati, OH, March 16-19, 1990).
PUB TYPE Viewpoints (120) -- Speeches/Conference Papers (150)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS *Aging (Individuals); Cancer; Life Satisfaction; Nursing Homes; *Older Adults; *Personal Autonomy

ABSTRACT

People in the counseling profession make some profound assumptions about the freedom that all people have (or seem to have). From the moment that each counselor began counselor training, the notion that people are able to generally choose and make decisions for themselves has been associated with the dominant process models of the profession. As a result, it is often difficult to imagine that some people as they grow older lose their freedom to make choices about their lives. Autonomy has been said to be similar to notions of self-determination, freedom, independence, etc. Autonomy gives a sense of well-being, but the older person may decrease his or her expectation of freedom of choice in order to retain a measure of life satisfaction. Situations in which individuals can lose their autonomy as they grow older include the diagnosis of cancer and nursing home placement and residency. The diagnosis of cancer may cause a person (or family) to surrender to the forces of medicine without considering the choices that are available. Another potential source for the loss of autonomy in adult life occurs with nursing home placement and residency. The nursing home carries with it images of the "last stop," a place where the poor, the frail, and the demented elderly go to wait to die. Counselors who work with persons in later life must constantly ask themselves what is truly best for the individual and consider too what allows them the most autonomy. (ABL)

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PRESERVING ELDER AUTONOMY: MORAL AND ETHICAL CONSIDERATIONS*

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*Presented at the 1990 Convention of the American Association for Counseling and Development in Cincinnati and enhanced from an article entitled "Autonomy in adult development and aging" in the Association for Adult Development and Aging Newsletter (1989, 3(Special), 12-15).

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Abstract

People in the counseling profession make some profound assumptions about the freedom that all people have (or seem to have). From the moment that each counselor began counselor training, the notion that people are able to generally choose and make decisions for themselves has been associated with the dominant process models of the profession. As a result, it is often difficult to imagine that some people as they grow older lose their freedom to make choices about their lives. In this article, there will be (1) an exploration of the concept of autonomy, (2) a look at the reasons for being concerned about autonomy, and (3) a discussion of two ways that autonomy can be lost by older Americans.

Autonomy: What Is It?

Collopy (1988) believes that autonomy is similar to the notions of "... self-determination, freedom, independence, liberty of choice and action"(p. 10). As such, it is in concert with the very values that underlie our national culture, for in the United States, we generally accept the idea that all people are, or should be, able to choose and act as they wish as long as no harm comes from the thoughts or actions.

Autonomy can be seen as having several dimensions

> It includes the freedom to shape long range goals and purposes, to determine life priorities and commitments, to control the content and direction of personal history. In more particular terms, it includes the freedom to manage the short range, ad hoc aspects of life, the mundane realities that measure self-determination on a day-to-day basis. (Collopy, p.10)

Thus, autonomy can exist as we make decisions in our minds as well as when we carry out those decisions (Collopy, p.11). Autonomy can be present when a person acts on his/her own or when that same person gives another the right to act as a delegate (Collopy, p.12). The concept of competence can also be a part of autonomy, for a person can engage in actions that are "...informed, rationally defensible, and judgmentally effective" (Collopy, p.13), or they can be making choices that are not competent and which are incapacitated (Collopy, p.13). The problem here is the determination of competence or informed autonomy.

In addition, autonomy can be seen along the polarity of authentic versus inauthentic, for in addition to rationality, autonomous decisions can be based on an "...individual's own personal values" (Collopy, p.11) or on those imposed by others.

> Authentic autonomy therefore consists in choices and behaviors that are deeply in character, that flow from past moral career and ethical style, as well as from present values and immediate self-shaping. (Collopy, p.14)

Collopy also discusses the notion of immediate and long range autonomy, and in so doing he distinguishes between freedom in the short-run and long-term freedom (p.15) Here, choices made for the immediate future may have limiting consequences in the long run. And, finally, there are positive and negative autonomy. Collopy defines the notion of negative autonomy as an obligation for "...others to stand back, not to overrule, block, or even meddle in the free choice and action of the individual" (p.16).

Whereas, positive autonomy

> ...proclaims entitlement, obliges others not simply to stand back and refrain from interference, but to step forward and provide resources, to offer instrumental means. (Collopy, p.16)

This latter form of autonomy implies helping and assistance as well as advocacy by others in the environment.

For Collopy (1988), the concept of autonomy is related to personal freedom and control over one's immediate and future life. It involves both decision-making and action, acting on one's own as well as giving others the right to act for one. Inherent in autonomy is the complicated issue of competence, but the rational base of a decision or action must be tempered with questions about one's personal values and morals. And, autonomy involves rights to both interference and support from others as well as non-interference. The problem for counselors is protecting individual autonomy while at the same time protecting the individual and being conscious of what we are doing when we are doing it.

Why Be Concerned With Autonomy?

The value to counselors in being concerned about autonomy is not only the intuitive sense that it is important as Americans to preserve the freedom of others, but also because "...lack of control has negative effects on emotional, physical, and behavioral well-being" (Hofland, 1988, p.3). Here, "lack of control" is equated with the loss of the ability to make decisions or to be autonomous. For George (1986),

> ...there is considerable evidence that life satisfaction is a function of adequate social and psychological resources, regardless of age. (p.7).

And, life dissatisfaction

> ...represents a discrepancy between real and aspired conditions of life. It can be reduced either by bolstering achievements or by lowering aspirations. It appears that many older adults lower their aspirations so that decreased social resources can be accommodated without a concomitant decrease in life satisfaction. (George, 1986, p.7)

It is apparent that autonomy gives a sense of well-being, but the older person may decrease his or her expectations of freedom of choice in order to retain a measure of life satisfaction.

When we talk about autonomy in the American culture, we are really dealing with an aspect of the concept of "quality of life". There is the desire by all of us to preserve the quality (hopefully high) of a person's life throughout all the days of their life. To carry out this value, efforts are made to insure an individual's ability to make choices, both decisions and actions, throughout the life span. When a person loses the ability to choose for him or herself on large issues or small, then the quality of life is diminished. The individual has lost something of themselves, and our society has also lost something fundamental.

Loss of Autonomy with Age

There are several situations in which a person can lose their autonomy as they grow older, and in this section, there will be a discussion of two of these, the diagnosis of cancer and nursing home placement and residency.

The Diagnosis of Cancer

The advances that have been made in medical technology have created the potential for us to survive cancer and its treatment. But, the very diagnosis of such an illness as cancer may cause a person (or family) to surrender to the forces of medicine without considering the choices that are available. Hofland (1988) discusses the "principle of beneficence" that

> ...directs the physician to promote and protect the best interests of the patient by seeking the greater balance of good over harm in treatment and care. (p. 4)

This principle is very paternalistic, because the physician frequently determines the best choices for the patient. With the high sophistication of modern medicine, paternalism is even more pronounced in those situations where physicians may fear that ill or disabled persons will "...make mistakes" (Hofland, 1988, p.4) when making their own choices. Dougherty (1985) describes three types of physician-patient relationships, and these are the passive patient, the cooperative patient, and the active participant patient. Clearly, for the preservation of autonomy, the model of preference is the one in which there is mutual participation in the decision-making regarding treatment or therapy.

In a life-threatening situation, are there choices? Heaney (1986) believes there are when we thoroughly understand the situation in which we find ourselves. In a remarkable article about a friend who has died of the surgical intervention for cancer, Heaney, a physician, describes his friend.

> He was a health professional himself; he knew he did have choices, and I believe his decision was about as free as temperament and circumstances ever permit. So the fact that the outcome of his surgical misadventure was not as he and I might have hoped is not the point of my present distress. Rather, it is the widespread notion that he and others like him have no choice, that he had to submit to a surgical assault that, for all its technical virtuosity, was not much different -- from the body's point of view -- from bearing the full force of a hand grenade explosion or a high-speed motorcycle accident. (p.316)

Heaney (1986) then asks the questions,

> What is this technological tyranny in which so many of us so willingly collude? In what other sector of our lives do first-world citizens experience such total capitulation, such unconditional surrender, as to the medical and surgical forces arrayed against cancer? It is a capitulation not to the enemy itself, but to the tyranny of forces that we hope may save us from that enemy. It is as if citizens of a democracy gave up their freedom and submitted to a dictatorship in order to ward off an external assault on that very freedom. Can we not see that the cure may sometimes be worse than the disease? And even when we do realize that, why do we still submit? (p.316)

In cases where there are choices, knowledge of the illness is important, but so too is the involvement of a neutral party to help with the decision. Although most counselors are not trained to assist with medical decision-making, this is an ideal role, because

> What is needed for most of us is some impartial third party to help in the decision process -- to help the surgeon to accept the fact that to do less than all he can is O.K., that he has not thereby been derelict, and to help the patient find the choice best calculated to optimize the time left, to maximize the real chances, to accept the symbolic loss of bodily integrity that the diagnostic label implies and to realize that doing less than all that is technically possible is not "quitting". (Heaney, 1986, p.320)

What are the best choices when one is confronted with cancer? How can a person be enabled to make his or her own choices? How can autonomy be preserved in the face of panic and the desire to escape from the life-threatening potential of this illness?

Nursing Home Placement and Residency

Another potential source for the loss of autonomy in adult life occurs with nursing home placement and residency. The nursing home carries with it images of the 'last stop", a place where the poor, the frail, the demented elderly go to wait to die (Cole, 1987).

> As the successor to the almshouse and state mental hospital, the nursing home retains characteristics of those institutions designed to house the most destitute and sickest at the least public cost. (Cole, 1987, p.15)

As a place where people have little control over their personal lives, the nursing home has a negative reputation, and recent popular media articles by Drew (1989) and Willard (1989) emphasize that autonomy can be severely limited in these facilities.

Nursing home placement involves four unique features (Moody, 1987). First, the decision is nearly always irreversible. Second, people want to avoid the stigma of placement, but they do want high quality care if they must be placed. Third,

> ...there is a problem in knowing what "involuntary" placement actually means. The problem of distinguishing voluntary from involuntary placement exists even from those who are mentally competent but deeply ambivalent or contradictory in their feelings. (Moody, 1987, p.16).

And, fourth, it is unclear who should make the placement decision and who, then, should carry the responsibility for it. The difficulty with the issue of placement is that it is often complicated by the frequent reality of families needing to make decisions while in a state of crisis. It is likely to be a group decision, made by caregivers, and accompanied by feelings of guilt (Moody, 1987).

Nursing home placement carries with it images and realities for the person being placed. For this individual, there is the feeling of hopelessness, for it is probably the beginning of the end of their life. It is a time when either one's body or mind, or both, has become unable to support them in daily activities, and someone perceives the need to provide a more helpful, supportive, and safe environment for the older person. Autonomy is lost when the decision is not the individual's, and it suffers further when residency involves invasions of privacy (e.g., sharing a room with someone previously unknown, having to bathe in front of others, or having strangers regularly enter one's room without knocking), unaccustomed regimentation (e.g., being placed on a schedule for eating, bathing, and bedtime, or having to eat food that is neither chosen nor liked), and assaults on one's personal integrity (e.g., being physically restrained, being called "Grandma" or

"Grandpa" or by one's first name by people who are neither known nor relatives, or having to associate with others in the nursing home who are confused and/or agitated).

For the family member and/or caregiver who engineers the placement of a loved one into a nursing home, there are also images and realities that relate to autonomy. The first is the phenomenon of guilt over not being able or willing to care for an older parent or spouse.

> Undoubtedly, nursing home placement in our society is commonly seen as a sign of moral failure. There are those who will whisper, "She put her mother away", implying that a child failed to care for a parent at home, even if such care might involve, in Daniel Callahan's (1985) phrase, "imperative duties and impossible demands". The sense of guilt is reinforced by widespread public skepticism about nursing homes. Critics from all parts of the political spectrum share the common American attitude that the nursing home itself is a moral outrage, an affront to what a "good old age" ought to be. (Moody, 1987, pp.16-17)

Second, there is the image of doing good by protecting the older person by placing them in the nursing home. Is this real, or is the decision made for the sake of autonomy for the person doing the placing? Or, is this the image that the medical authorities would like the person doing the placing to believe? And, third, there is the reality of the expense of nursing home care and the consequences to many families. Autonomy for the individual in the nursing home can be seriously jeopardized when financial resources are depleted and that individual becomes indigent in order to protect the integrity of the rest of the family.

Conclusion

This paper has only briefly touched some of the issues involved in a look at autonomy in the lives of older persons. As counselors who work with persons in later life, we must constantly be aware of those acts by ourselves and others that restrict the autonomy of clients, friends, and relatives. We do take so much for granted, but if we look at the goal of preserving freedom of choice in the lives of others, then we must consider the many aspects of illness and nursing home placement and residency that limit a person and their family. As counselors, we must ask what is truly best for the individual and consider too what allows them the most autonomy. For without the freedom that we have taken for granted for most all of our lives, life certainly has restricted meaning.

Recent research must be mentioned as an after-thought. First of all, many medical decisions are being made, today, for seemingly incapacitated older persons based upon what family members (proxies) believe the incapacitated person would choose. Zweibel and Cassel (1989) conducted a vignette-based study to test the ability of proxies to make choices for patients, and their results call into question whether this process can work without clearly written instructions from the patient. In another study, "decisionally capable" nursing home patients

> ...were more likely to forego life-sustaining measures than those of questionable capability. The vast majority of proxies disapproved of using life-sustaining measures, even in some cases with limited knowledge of patients' preferences. (Diamond, Jernigan, Moseley, Messina, & McKeown, 1989, p.622)

Tomlinson, Howe, Notman, and Rossmiller (1990) assessed substitute judgment and found support for this practice but expressed concern over the indiscriminate use of durable power of attorney. And, finally, Jecker (1990) discusses autonomy and intimacy with emphasis on the ability of intimates to better know the values of their loved ones. Obviously, further research in the preferences and performance of proxies is vital.

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